

Never too young.

Bowel cancer can
strike at any age.



Bowel cancer. It's our national emergency.

We have one of the highest rates of bowel cancer deaths in the Western world.

While screening, when finally introduced, will reduce mortality rates in those aged 60-74 years, New Zealand is seeing increasing rates of bowel cancer in the under 50 population.

Doesn't bowel cancer affect older people?

It does – 90% of patients are over 50.

But it affects younger people too.

Every year, more than 300 people under 50 are diagnosed with bowel cancer. This isn't an insignificant number – it's nearly the same as New Zealand's road toll deaths.

Unfortunately, younger patients are often finally diagnosed when it is too late for effective treatment.

This can be due to lack of appreciation of the significance of bowel cancer symptoms, by them, their doctors, and those accepting referrals for specialist appointments.

The problem? They are considered too young, too healthy, too fit, and many remain undiagnosed for months or years before presenting with advanced bowel cancer.



Don't sit on your symptoms

The Never Too Young public awareness campaign has been put together by one of our community ambassadors in collaboration with Bowel Cancer New Zealand, specifically to raise awareness of bowel cancer in younger adults.

It encourages young people to talk to their GP if they have experienced symptoms including:

- Bleeding from the bottom (rectal bleeding)
- A change in bowel habit for several weeks
- Fatigue and tiredness
- Any lumps in the abdomen
- Unexplained weight loss

Symptoms may come and go and often people will wait and hope it goes away. When it does (even for a while) this can provide false reassurance.

Routine diagnosis questions

- Have you had a recent change in bowel habit to looser, more diarrhoea - like motions, going to the toilet more, or trying to go?
- Any bleeding from the bottom, or blood in the bowel motions?
- Have you had any other symptoms like straining, soreness, pain and itchiness? (This may indicate piles but it's important to confirm this)
- Have you experienced any abdominal pain?
- Have you lost weight or become more tired recently?
- Do you have a family history of bowel cancer?

Many colorectal cancers do not cause any symptoms in the early stages. They can grow for years while the patient feels perfectly healthy. When clinical symptoms consistent with bowel cancer occur, early investigation is important.

Speaking up for your patient

People don't visit their GP to talk about their bowels unless they are concerned something is wrong.

Squeamishness and cultural differences may keep many people away, so when they do present with symptoms, they need you to listen closely to their concerns and ask about their family history.

Your patients presenting with symptoms, or for whom you have clinical concerns, need you to take a very careful history, ask about their family members affected by bowel cancer, and to report this information carefully and completely on a referral you may make for a first specialist assessment. Comprehensive, accurate information is critical to your patient's referral.

The steps to diagnosis

1. Dig a little into their history. Has a family member had bowel cancer? Are there any other symptoms they might have missed?
2. A full anorectal and abdominal examination only takes a few minutes and is an important first step in diagnosis.
3. Do they have health insurance? Or can they privately fund a colonoscopy or CT colonography?
4. Some DHB's have rectal bleeding clinics which are accessible to all, such as the Charity Hospital in Christchurch.
5. Importantly, if you have clinical concerns about your patients, keep listening to them and referring them to specialist services until an appointment for consultation, examination, and a possible diagnosis can be made.



Colonoscopy referrals

Triaging is only as good as the information provided by the referrer.

Do you have a symptomatic patient? Here's what to put in your colonoscopy referral.

1. For change in bowel habit referrals, include:
 - Mode of onset (sudden e.g. post infection, or gradual)
 - Duration
 - Persistence/progression vs fluctuating symptoms (with specifics of latter)
 - Presence of associated symptoms – bleeding, weight loss, pain, tenesmus (with specifics)
2. Always include any prior colonoscopy or CT colonography history, preferably who performed it, where it was done, date, specific findings and histology.
3. If the public sector does not provide a specialist assessment, you could ask your patient if going to the private sector is an option for them.
4. Clear unambiguous language in the referral – refer to the referral criteria, do not include large amounts of extraneous information if you are requesting a first specialist assessment for a direct access colonoscopy.

Family history referrals

1. For all family history referrals you must include specific ages of affected relatives (e.g. “aged 52 at diagnosis” not “in their 50s”), and specific relationship of affected relatives (e.g. father and paternal grandmother)
2. For complex cases e.g. colorectal cancer plus other cancers in close relatives, or relative with “lots of polyps,” an initial referral to Familial GI Cancer Service is recommended. Patients can self refer to this service.



Hear our stories

10% of Bowel Cancer patients are under 50 – that's more than 300 a year. Bowel Cancer can strike at any age.



My name is Chelsea Halliwell

Age at diagnosis: 39

Symptoms:
Intermittent blood in stool

Duration of symptoms:
6 weeks

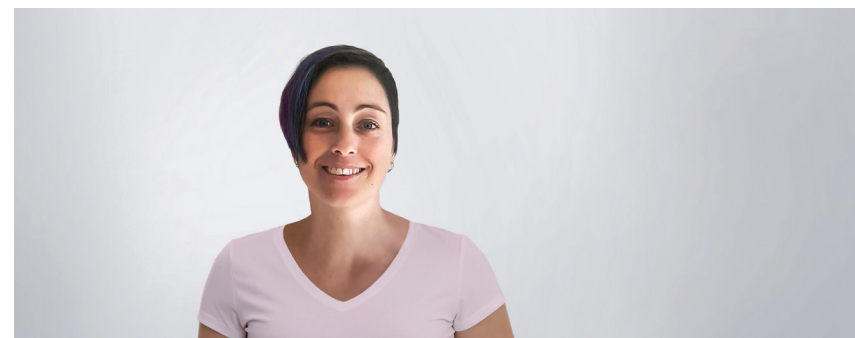
Diagnosis: Stage 3 bowel cancer

Treatments: Subtotal colectomy with sigmoid anastomosis and 12 cycles of Folfox chemotherapy.

My story:

I was 39, fit, healthy and bullet-proof. And then I was diagnosed with bowel cancer. Because of my health insurance, things moved quickly for me – my surgeon told me that another six months would have made all the difference for my prognosis.

I'm incredibly grateful to my GP for referring me through so quickly.



My name is Fiona Cullen

Age at diagnosis: 38

Symptoms:
Bleeding, anaemia and low B12, change in bowel movements, weight loss, stomach pain

Duration of symptoms:
18 months

Diagnosis:
Stage 4 metastatic bowel cancer

Treatments:
28 cycles chemoradiation, colorectal surgery, 8 rounds Capox chemotherapy, ongoing palliative chemotherapy.

My story:

Because I was in my late 30s, I went through a drawn-out process and delays including being denied a specialist appointment twice. Finally, while 30 weeks pregnant, I received the devastating news that I had bowel cancer and then received a colonoscopy and other scans.

I was disappointed that your age is a barrier to being seen and diagnosed with bowel cancer. My experience of an earlier breast cancer scare couldn't have been more different, being pushed through extremely quickly for what turned out to be a non-cancerous growth.

Now a mum to nearly two-year old Morgan, I'm fighting to be there for each and every precious moment.

Each year
about 3,000
New Zealanders
are diagnosed
with the disease
and more than
1,200 will die.



My name is Anaru Turei Gray

Age at diagnosis: 38

Symptoms:

Ongoing irritable bowel-type symptoms then substantial blood in stools for three months prior to diagnosis

Duration of symptoms:

Irritable bowel-type symptoms for years, bleeding for three months

Diagnosis:

Stage 4 metastatic colon cancer. Mid-sigmoid bowel, surrounding lymph nodes, and wide-spread liver cancer

Treatments:

Folfox chemotherapy, mid-sigmoid colon resection, minor left lobe liver resection.

My story:

I was fortunate that my GP was thorough and followed up on my test results. He was quick to refer me for acute treatment at the hospital. I only wish that I saw him earlier, even in that first week that I had that bad bleeding. With aggressive cancers every day, week, and month counts towards getting much needed treatment.

It is a big thing for a Māori male to go to the doc about something so personal. I'm grateful my GP had multiple tests taken ASAP - that is the best thing he could have done.

He kai kei ōku ringa

Now, I'm focused on being happy, eating well, and getting enough activity and rest. We, as patients, have the ability to make positive changes that benefit our health and reduce our disease.



My name is Jenny Cameron

Age at diagnosis: 26

Symptoms:

Anaemic, blood within the stools, unexplained weight loss, low energy, severe GI discomfort, pain, and alternating diarrhoea and constipation

Duration of symptoms:

16 months

Diagnosis:

Stage 3 Dukes C1 colon cancer in descending colon with lymph node involvement

Treatments:

Sub-total colectomy, Folfox intravenous chemotherapy and Capecitabine oral chemotherapy.

Despite displaying all of the symptoms of bowel cancer, I was put in the box of “young, fit and healthy”. I was young and fit, but I wasn’t healthy.

Blood and stool tests were not done. Instead I was put on a non-urgent colonoscopy wait-list under public care and told to eat more fibre and take peppermint tea. I presented with a major bowel obstruction at A&E long before my colonoscopy was due.

In hindsight, continuity of care was an issue in my situation. I saw several different doctors in the 16 months at my large and busy GP practice. My persistent symptoms were not connected together and I was essentially ‘lost’ in the system.

I’m left with questions about ‘what if’ I was diagnosed earlier. It’s taken some time, with mediation through the health and disability commissioner, to begin my healing process without anger. I am very proactive with my health care now and I encourage those around me to be as well.

No 26-year-old should have to go through what I went through – we need to change the conversation and smash the belief that this is an older person’s disease.



My name is Britt Chambers

Age at diagnosis: 31

Symptoms:

Fatigue, low iron, change in bowel movements, severe stomach cramps

Duration of symptoms:

6 years

Diagnosis:

Stage 4 bowel cancer

Treatments:

Surgery, Folfox chemotherapy.

My story:

My stage 4 bowel cancer was undiagnosed for 6 years, with my symptoms being put down, at various stages, to my subpar diet and my training as an elite athlete, gluten intolerance, or an ‘appendix mass’.

Unfortunately, because of the length of time it was left to grow, the cancer has spread to my lungs and is in lymph nodes around my body.

I’ve been told I was never tested because I was ‘too young’ to have something like bowel cancer.

If I’d known I could self-fund a colonoscopy I’d have done that - a couple of thousand dollars cost to personally fund a colonoscopy is a small price to pay for an early diagnosis.



My name is Anna Kooperberg

Age at diagnosis: 32

Symptoms:

Fatigue, low iron, change in bowel movements, severe stomach cramps

Duration of symptoms:

2 years

Diagnosis:

Stage 2 bowel cancer

Treatments:

Total colectomy and ileorectal anastomosis (no bag) + 8 rounds chemotherapy (oral capecitabine).

My story:

I was fit and healthy and didn’t fit the profile of a bowel cancer patient, apparently, with no family history. I had all of the symptoms; including very bad stomach cramps, blood in my

stools, low iron, loss of appetite, fatigue. I was given multiple rounds of iron tablets that had little impact and there was a lot of discussion about IBS and the FODMAP diet.

I was never referred on for a colonoscopy by my GP. I was lucky enough to have private medical insurance and so referred myself on the advice of a friend.

Due to my age I went through IVF in between surgery and chemo to freeze my eggs.

If I’d not referred myself when I did I believe I would’ve ended up in emergency surgery and a much bleaker outcome. I’m grateful that it was discovered when it was.



**Bowel Cancer kills
four times more
New Zealanders
than the road
toll, and as much
as breast and
prostate cancer
combined.**



My name is Jonny Hope

Age at diagnosis: 34

Symptoms:

Stomach cramps, fatigue,
diarrhoea and anaemia

Duration of symptoms:

3 months

Diagnosis:

Stage 3 Colon Cancer

Treatments:

2/3rds of large intestine removed
and 6 months of chemotherapy.

I had stomach cramps that fluctuated in intensity over a period. After three months, I went to the doctor. Blood tests revealed I was anaemic, and after more tests I was booked in for a colonoscopy and gastroscopy.

After a few weeks I'd still not been allocated the procedures when I had severe stomach cramps, so I was pushed through as urgent. I had my colonoscopy and gastroscopy the next week, which revealed a 6cm cancerous tumour in my transverse colon.

Prior to diagnosis I have always been fit and healthy. I eat well, I exercise, look after myself, I've had no other diseases. Results revealed no genetic evidence for the cancer being hereditary, no indication of it being diet related.

Just bad luck.

I've tried to be open and positive about all this as I don't see any reason not to be. I think realistically everyone's going to have some experience with cancer at some point in their life; if not personally then someone they know. The main thing is to encourage people to not sleep on any symptoms. Go see a doctor, get it checked out. Catching it early is paramount and often means it's more treatable or manageable.



My name is Sarah Lambourne

Age at diagnosis: 38

Symptoms:

Tiredness, unpredictable bowel habit, frequent diarrhoea, put down to food allergies or irritable bowel

Duration of symptoms:

2 years

Diagnosis:

Stage 3 upper rectal cancer

Treatments:

Chemoradiotherapy, excisional surgery followed by Folfox chemotherapy.

My story:

I noticed blood intermittently for three weeks before going to the doctor. After diagnosis, I learnt about the symptoms of bowel cancer, and realised I had actually been experiencing symptoms for about two years which had been put down to other factors.

I'm now fit and healthy, but when young women experience bowel cancer it affects more than just their bowel. I lost my fertility. I had to have a hysterectomy and I went into early menopause.



My name is Brad Beveridge

Age at diagnosis: 36

Symptoms:

Change in bowel movements, minor blood spotting

Duration of symptoms:

Two months

Diagnosis:

Stage 3 colon cancer

Treatments:

Resection of upper rectum and sigmoid colon. 12 rounds of Folfox chemotherapy.

My story:

I was a fit and healthy, not quite middle aged, guy. I probably would have managed to ignore my symptoms in a manly fashion for longer, except a very good friend of the same age had died from bowel cancer a year earlier so my awareness was raised.

My GP was concerned I'd not get a colonoscopy via the public system, but he was prepared to advocate strongly on my behalf. Luckily I had private health insurance and my colonoscopy happened quickly.

Early detection saved my life, but my window for action from first symptoms was narrow.



My name is Solon Fakalata

Age at diagnosis: 41

Symptoms:

Occasional blood in stool, bouts of diarrhoea, fatigue, fever and nausea

Duration of symptoms:

12 months

Diagnosis:

Stage 4 Colorectal Cancer (Liver metastases)

Treatments:

Pre-operative chemotherapy and radiotherapy running concurrently, Open Ultra-low Anterior resection to remove tumour and involved lymph nodes. Post-surgery: Ileostomy bag for 7 months. Second surgery: close loop, ileostomy reversal.

Working in construction and putting in long hours I put a lot of my symptoms down to the nature of my occupation. I didn't think much of it until one day I realised having two young children aged 5 and 3 years old, I owed it to them and my wife to get my health in order. I went to the GP requesting a full check-up and specifically requested a Bowel Screening Kit. The test came back positive instigating a specialist referral and colonoscopy which resulted in the identification of a 10cm tumour in the colon. A further PET scan identified that it had spread to the liver, with a Stage 4 colorectal cancer diagnosis.

I was clear for 2.5 years but have since had a recurrence of nodal metastases and am currently undergoing treatment.

I look to the positives and the fact that I proactively made the call to my GP. I often think if I hadn't taken that action would I still be alive today? Currently I still have a battle on my hands, but at least I like to think my actions have allowed me to spend more time with my family, watching my children grow up.



My name is Kathy Sullivan

Age at diagnosis: 36

Symptoms:

Irritable bowel / food intolerance type symptoms, very changeable bowel motions, bloating and general not 'feeling right', some intermittent blood in stools

Duration of symptoms:

Several years

Diagnosis:

Stage 3 Rectal Cancer

Treatments:

6 weeks chemotherapy and radiotherapy, surgery: tumour removal and ileostomy placed, then ileostomy reversal, chemotherapy, hernia repair surgery a year after treatment.

My story:

I was active and health conscious, and I turned to Dr Google when I thought my symptoms were down to food intolerances. I wish there was more awareness of how bowel cancer affects younger people, both male and female.

I'm so grateful to my GP who decided to investigate some of my concerns further and do some simple tests in surgery that alerted her that there was something more serious going on.

Bowel Cancer
is curable in
more than
75% of cases if
caught early.

It's never too young.
We need your support.

www.nevertooyoung.org.nz



Bowel Cancer
AWARENESS MONTH